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AUTHOR Rasbold, Ruth-Ann
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ABSTRACT

Since Part H Interagency Coordination Councils (ICCs) were established in 1986, parents have been discussing what the primary role of the parent member is and should be, such as providing a parent and family perspective to the work of the ICC or representing family consumers throughout their state and, as such, a wide range of needs and opinions. By their presence in ICC meetings and on subcommittees, parent members can infuse a family perspective into all conversations or, in a more active role, they can infuse this perspective into program policy and even into the processes of the ICC itself, assuring that the Council supports the participation of its parent members in all its practices. This "Early Childhood Bulletin" explores ways that parent ICC members can enhance and expand their capacity to reflect a broad diversity of family perspectives. Strategies and reasons for gathering information are summarized, and information on the use of focus groups and surveys is presented. Also included are lists of references and information resources. (SG)

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COALITION QUARTERLY
EARLY CHILDHOOD BULLETIN

RESEARCH STRATEGIES FOR STRENGTHENING
YOUR WORK ON THE ICC

By

RUTH-ANN RASBOLD

FALL/WINTER

1994

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News by and for Parents and Parent Members of State Interagency Coordinating Councils

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC-TAS

1994

**By Ruth-Ann Rasbold, Early Childhood Specialist
Federation for Children with Special Needs, Boston, Massachusetts**

By their very presence in ICC meetings and on subcommittees, parent members can infuse a family perspective into all conversations. Taking a more active role, they can infuse this perspective into program policy and even into the processes of the ICC itself, assuring that the Council supports the participation of its parent members in all its practices. This *Early Childhood Bulletin* explores ways that parent ICC members can enhance and expand their capacity to reflect a broad diversity of family perspectives.

Regardless of how you or others perceive your role on the ICC, you need information to participate effectively. Sometimes this information is readily available, and sometimes it is information that you have to gather by yourself or with others. In gathering information as an ICC member, you may collaborate with others in planning and conducting the research; you may initiate a project within the ICC, taking a leadership role in identifying a need for information and in formulating a strategy for getting that information; or you may gather information on your own to strengthen your own knowledge or to get to know what families throughout your state see as priorities. In any case, this article will give you some ideas of why and how you can go about gathering the information you need.

In the context of the ICC there are three reasons why you may want to gather information. The first is to become and to continue to be effective in your role. Information can shed light on how to proceed and how to be effective in any new or unfamiliar situation. For example, you may want to gather information about the ICC and how it works, about its history (how did we get where we are), about policies and legislation, and about the issues and topics which are currently "hot" in your state and nationally.

The second reason is to support your own opinions, or those of your committee or group. What you are promoting may have precedent in practice or in research, in your own state or elsewhere. Knowing what has been or is being done and why, strengthens your own arguments.

The third reason to gather information is to find out what people think. The ICC as a whole may conduct public hearings and declare public comment periods as

ways to test proposed policies or programs. However, if you have been charged with or feel that you are representing families throughout your state, you may need to develop ways to hear from them directly about specific topics.

Useful tools

For all three purposes, there are a variety of approaches. The tools you use will depend on the information you are trying to find, its complexity, the reason for gathering it, and how you will use it.

The most informal way to begin is by talking to people you know: other parents, ICC members, and professionals you have met through services for your child. Expand your network of trusted colleagues by contacting new people, especially veteran ICC parents both within and outside your state. By talking informally to people you know and building your network of friends and colleagues, you can get a sampling of current opinions on a topic, find out what has been done in the past, and learn about other resources, (i.e., people, organizations, books, articles). Talking with other people also can help you clarify the question(s) you are asking.

To get a formal, sometimes more objective, perspective on a topic, look at written materials. Organizations that specialize in early intervention and related areas are good sources of information about best practices in serving children and families, about policies that have been developed, about national trends and happenings in other states, and about research that has been done on other topics. Several key resources listed in the resource section on page six of this *Bulletin* can provide you with some ideas to get you started. Look to minutes of ICC meetings, reports from past ICC work, and data from your Part H lead agency or other agencies in your state for information about your own state's programs and policies.

There are times, however, when you want new information. For example, you may want to hear from other families (your constituents) about their own experiences, their opinions on issues or actions currently being considered by the ICC, or other topics. Direct access to the opinions and perspectives of a cross-section of parents of children with disabilities is not readily available to most ICC parents because, unlike most other ICC members, they usually do not represent a

formal organization or agency. Therefore, they do not automatically have a mechanism for gathering constituent opinion. Two methods for obtaining this information are surveys (mail or telephone) and focus groups (see boxes).

In addition to providing insight into the issue you are investigating, gathering information from your constituents has two other benefits. First, it provides an opportunity for a greater number of consumers to be involved in policy making in the state. Second, it can create or reinforce a consumer orientation for the work and the process of the ICC.

The question is the key

Whether you are looking for something as simple as the views of the membership of your ICC on a particular issue, or as complex as best practices in service coordination, the key to successful research is asking the right questions. Create questions that focus your research. The more exact you can be from the start, the more success you will have in finding the information you want.

However, as you begin talking with people and reading (that is, as you begin your research), you may find that the focus questions need to be refined. They may need to be narrowed, broadened, or changed altogether. As you refine your questions, the direction of your search becomes clearer.

Although families often have been the subjects of research, parents seldom have initiated research efforts. Indeed, statistics and validation studies may seem very academic and intimidating. Yet research in its broadest sense is simply gathering information. Gathering information may be as straightforward as having a conversation—asking a question and recording the answer. This article is not intended to be a treatise on academic research. It is intended to provide parents with some basic tools that will guide them in designing conversations that will help them better represent the families they serve on the ICC.

Ultimately, research and advocacy belong together. The voices of families—both as providers of information and as researchers—must be heard in the dialogue that is shaping the future of family-centered care and services.

What Have You Done?

We invite you to contact Ruth-Ann Rasbold at the Federation for Children with Special Needs to discuss ways that you have gathered information to strengthen your work on the ICC, both as a collaborator and as an initiator of research. A follow-up article, giving examples of information-gathering activities from *ECB* readers, will appear in a future issue.

Summary of Information Gathering Strategies

1. Formulate a clear focus question: What do you want to know?
2. Talk about your concerns/questions with others, i.e. ICC parents, other ICC members and/or other colleagues. In addition to gathering more information, this will help generate interest and support for your project.
3. Modify, clarify and narrow your question as you proceed.
4. Identify the kind of information you need to answer the question:
 - ◆ Do you need to know what researchers have found?
 - ◆ Do you need to know what happens day to day in a program or agency?
 - ◆ Do you need to know the policies of particular agencies?
 - ◆ Do you need to know the opinions of families or practitioners?
5. Plan your research efforts:
 - ◆ Identify who might know some of this information or where you can find it.
 - ◆ Identify your information gathering method:
 - informal • literature searches, reviewing research studies
 - surveys • focus groups, other
 - ◆ Identify who can help you gather this information:
 - librarian • lead agency staff
 - parent groups • spokesperson/liaison connected with a specific community or group

Upcoming NEC*TAS Meetings

NEC*TAS is sponsoring two events available to parents and all NEC*TAS clients, including ICC chairs, Part H and 619 coordinators, and EEPD Projects.

DATE	CONFERENCE	PLACE
April 25, 1995	A national video teleconference on "Strategies for Helping Young Families Affected by Alcohol and Other Drugs"	(Call NEC*TAS in Chapel Hill for a list of state participants.)
July 31 - August 2, 1995	Partnerships for Progress (Contact ICC chair for more information.)	Arlington, Virginia

Other smaller group meetings are held in response to interest expressed in the technical assistance needs assessments done in Fall 1994. Parents are represented on many state delegations.

Focus Groups

For the purposes of the ICC, focus groups can be used to:

- inform or assess proposed policy and practice;
- examine how people receiving or providing services feel about programs and specific aspects of those programs; and
- find information on the implementation of the law and practices.

Typically, several groups will be interviewed to compile information about a given question.

Skinner (1994) says that,

In a focus group interview, a moderator leads 6 to 12 individuals in a 1- to 2- hour discussion centered around a specific issue. Participants are asked about their perceptions of and perspectives on various programs, services, and policies. The moderator typically asks only 4 to 10 open-ended questions. Otherwise the moderator participates only to the extent necessary to probe, encourage everyone to express his or her opinions, and help the group stay on track. The interaction among the participants and the expression of multiple perspectives are the significant features of a focus group. In the analysis of the data, the researchers look for points of consensus and disagreement, and the process by which this consensus or conflict emerges. (p. 5)

Focus group interviews must be carefully designed. Here are some basic design suggestions:

- Work with your ICC or other group to clearly articulate the focus question.
- Contact participants in writing and by phone one or two weeks before the meeting.
- Give participants a brief description of who is doing the research, why it is being done, who is sponsoring it (e.g., the ICC, the lead agency), and what will be done with the results.
- Assure participants that their answers will be confidential.
- Plan the session by deciding the interview questions to be asked, how the discussion will be conducted, and who will be in the groups.
- Plan the logistics to enhance, not hinder, the process.
- Use a comfortable room and set it up before the participants arrive.
 - ✓ Use name tags or tents.
 - ✓ Prepare for the inevitable: have extra tapes, batteries and extension cords.
 - ✓ Plan who will sit where.

Find a moderator who is skilled in objective facilitation and group process.

For more information:

- Bender, D.E., & Ewbank, D. (1993). *The focus group as a tool for health research: Issues in design and analysis*. Paper presented at the Social Science Plenary Session at the Annual Meeting of the International Clinical Epidemiology Network, Bali, Indonesia, January 1992.
- Greenbaum, T. (1988). *The practical handbook and guide to focus group research*. Lexington, MA: D.C. Heath and Company.
- Krueger, R.A. (1988). *Focus groups: A practical guide for applied research*. Newbury Park, CA: Sage Publications.
- Skinner, D. (1994). *Use of focus groups in qualitative evaluation methods*. Presentation at the NEC-TAS EEPCD Evaluation meeting, Seattle, WA, June 1994.
- Stewart, D., & Shamdasani, P. (1990). *Focus groups: Theory and practice*. Newbury Park, CA: Sage Publications.

Surveys

The purpose of a survey is to produce statistics, that is, a quantitative or numerical description of some aspect of those surveyed. You do this by asking people questions either by interview (in person or by phone) or in writing. In a survey you collect information from a fraction — a sample — of a group, not the whole group.

Designing the survey questions:

- Word the questions carefully so that they are easy to understand, and do not lead a person to answer in a certain way.
- Define any terms you use. For instance, terms like *early intervention* mean different things to different people. Be as specific as you can.
- Consider the format of the questions: open vs. closed and scales (numeric, continuum, agree/disagree). Each type has advantages and disadvantages in administering the survey, in getting the information you need, and in compiling your data.
- Make sure your survey questions will give you the information you need to answer your focus question.

Designing the format:

- Give clear instructions: written surveys should be self-explanatory.
- Put your questions in a form that will be easy to respond to. Make the layout of your survey simple, easy to read, clear, and uncluttered.

Before you survey:

- Test it. Try it out with colleagues and other parents. Ask for suggestions on making it better, easier, and more understandable.
- If your survey is done by interview (either in person or by telephone), train the interviewers so that they do not affect the response. Interviewers need to be trained in how to present the survey; how to ask the questions; how to probe when answers are inadequate; how to record answers; and how to interact with the person they are interviewing.

Consider your respondents:

- Time is valuable: design the survey to take less than a half hour to complete.
- Give a brief description of who is conducting the survey, why it is being done, who is sponsoring the research (e.g., the ICC, the lead agency), and what will be done with the results.
- Assure respondents that their answers are confidential, and that their participation is voluntary.

For more information about how to design and conduct surveys:

Fowler, F.J. (1993). *Survey research methods*. Newbury Park, CA: Sage Publication.

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Information Resources

- Your state's lead agency; your ICC staff
 - Your state's Department of Education
 - Colleges in your area
 - University Affiliated Program (UAP) in your state
-
- **NEC*TAS: Coordinating Office**
500 NationsBank Plaza
137 E. Franklin Street
Chapel Hill, NC 27514
(919)962-2001
 - *and NEC*TAS subcontractors:*
 - **Federation for Children with Special Needs**
95 Berkeley St., Suite 104
Boston, MA 02116
(617)482-2915 (Voice/TDD)
 - **Georgetown University
Child Development Center**
3307 M Street, N.W.
Washington, D.C. 20007
(202)687-5000
 - **National Association of State Directors
of Special Education (NASDSE)**
1800 Diagonal Road, Suite 320
King Street Station 1
Alexandria, VA 22314
(703)519-3800 (Voice)
 - **Hawaii University Affiliated Program
University of Hawaii at Manoa**
1776 University Avenue, UA4-6
Honolulu, HI 96822
(808)956-6449 or 956-5006
 - **ZERO TO THREE/National Center
for Clinical Infant Programs (NCCIP)**
2000 14th Street, North, Suite 380
Arlington, VA 22201-2500
(703)528-4300
 - **TAPP Focus Center on Early Childhood
Pilot Parents Partnerships**
2150 East Highland Ave., Suite 105
Phoenix, AZ 85016
(602)468-3001 (Voice/TDD)
 - **Early Childhood Research Institute on Substance Abuse
University of Kansas, Juniper Gardens Children's Project**
1614 Washington Blvd.
Kansas City, KS 66102
(913)321-3143
 - **Early Childhood Research Institute: Service Patterns and
Utilization, A Collaborative and Systems-Based Investigation
Carolina Policy Studies Program
Frank Porter Graham Child Development Center**
300 NationsBank Plaza
CB #8040
University of North Carolina at Chapel Hill
Chapel Hill, NC 27599-8040
(919)962-7374
 - **Early Childhood Research Institute on Inclusion**
Room 512 Kirkland Hall
Peabody College, Vanderbilt University
Nashville, TN 37240
(615)322-2249
 - **National Information Center for Children
and Youth with Disabilities (NICHCY)**
P.O. Box 1492
Washington, D.C. 20013
(800)695-0285
 - **Beach Center on Families and Disability**
3111 Haworth Hall
University of Kansas
Lawrence, KS 66045
(913)864-7600 (Voice/TDD)

EARLY EDUCATION PROJECTS FOR CHILDREN WITH DISABILITIES (EEPCD) — 112 federally funded programs for demonstration, outreach and dissemination of best practices in early childhood. A directory which includes a description of each of these projects is available from NEC*TAS for a nominal fee.

PARENT TRAINING AND INFORMATION (PTI) CENTERS — 66 federally funded programs throughout the country which provide specific assistance to parents and family members of children with disabilities. Contact NEC*TAS at the Federation for Children with Special Needs, 95 Berkeley St., Suite 104, Boston, MA 02116, for information about PTIs.

ELECTRONIC ACCESS — Commercial on-line telecommunication services (such as America On-Line or CompuServe) or the public access system Internet; both commercial and public bulletin boards and news groups on disability issues, including some specifically concerning early intervention, young children, and families.